



## Statutory Review of the Data Availability and Transparency Act 2022

To:

Dr Stephen King

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### ABOUT ANDHealth

ANDHealth is Australia's only organisation specialised in accelerating commercialisation of evidence-based digital and connected health technologies. We work with Australian digital and connected health companies to commercialise and scale their evidence-based technologies through the entire commercialisation pathway, from idea to exit. ANDHealth's investment readiness program suite and non-dilutive investment programs prepare companies for institutional investment and global enterprise customers and have been proven to positively impact both the number and maturity of companies in the Australian evidence-based digital and connected health sector. ANDHealth has prepared this submission in consultation with its partners and the broader ecosystem of over 1,000 evidence-based digital health companies with which it works.

ANDHealth would like to thank the Department of Finance for the opportunity to participate in this consultation and provide feedback on behalf of Australia's digital and connected health sector.

**If you have any questions, please don't hesitate to contact us:**

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## BACKGROUND

ANDHealth supports over 1,000 digital and connected health SMEs across Australia, providing unique commercialisation capabilities to our digital and connected health innovators, enabling them to realise greater patient impact, faster. Participants in ANDHealth's flagship programs have impacted over 2.3M patients in six years, undertaken >1000 clinical studies and pilots, generated and re-invested almost \$60M of new revenues, and attracted over \$216M in additional financing. In addition, ANDHealth works closely with a network of more than 30 industry partners spanning biopharmaceutical, medical devices, accelerators, incubators, investors and health providers.

ANDHealth welcomes the opportunity to provide feedback to the statutory review of the Data Availability and Transparency Act 2022 (DAT Act). As Australia's national digital health initiative supporting the development and commercialisation of evidence-based digital health technologies, ANDHealth strongly supports reforms that unlock the value of public sector health data while maintaining robust privacy and security safeguards.

## AUSTRALIA'S HEALTH DATA PARADOX

Australia is home to some of the world's richest, most comprehensive health datasets. Assets curated by agencies such as the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), and Services Australia provide an unparalleled foundation for evidence-based health policy, research, and innovation. These linked datasets capture the full spectrum of the health journey - from primary care and prescriptions to hospital admissions and outcomes - and have the potential to transform our health system, drive innovation, and improve patient outcomes at scale.

Yet, despite this promise, these national data assets remain largely inaccessible to expert analytic organisations outside government and select academic institutions. This bottleneck is not due to a lack of regulatory safeguards or technical capability, but rather to restrictive access policies and slow, inconsistent processes that have not kept pace with the needs of a modern, digitally enabled health system.

## THE IMPACT OF INACCESSIBILITY ON INNOVATION AND HEALTH OUTCOMES

### 1. Missed Opportunities for Innovation and Evidence Generation

The current legislation in the Act, which restricts access to accredited government and academic entities and requires project-by-project approvals, has created barriers for digital health innovators and expert analytics organisations. This has several direct impacts:

- **Global Competitiveness:** Australia is falling behind international peers such as the UK (NHS Digital) and Canada (ICES), where trusted private and not-for-profit organisations can access de-identified, linked health data for public-benefit research under robust governance<sup>1</sup>.
- **Stifled Innovation:** The inability to access timely, high-quality data means that the development, validation, and scaling of new health technologies is slowed or diverted to other jurisdictions<sup>2</sup>.

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<sup>1</sup> Digital Health Cooperative Research Centre, *A Call to Action for a National Data Governance Framework* February 2023 [https://researchaustralia.org/wp-content/uploads/2023/02/DHCRC-Call-to-Action-for-a-National-Data-Governance-Framework\\_Feb-2023\\_FINALDESIGNED-1.pdf](https://researchaustralia.org/wp-content/uploads/2023/02/DHCRC-Call-to-Action-for-a-National-Data-Governance-Framework_Feb-2023_FINALDESIGNED-1.pdf)

<sup>2</sup> Australian Healthcare and Hospitals Association (AHHA). *Australians missing out on technologies enabling data-driven improvements in health outcomes*. June 2022. <https://ahha.asn.au/australians-missing-out-on-technologies-enabling-data-driven-improvements-in-health-outcomes/>

- Patient Impact: Most importantly, patients miss out on timely interventions, improved care pathways, and access to innovative therapies—especially in areas of high unmet need such as rare diseases, chronic conditions, and rural or disadvantaged communities<sup>3</sup>.

## 2. Underutilisation of Publicly Funded Assets

Despite being publicly funded, many health data collections are only partially accessible or not accessible at all to those best placed to extract value for the health system. This results in:

- Underuse of valuable data assets
- Duplication of research efforts and inefficiencies across the system
- Missed opportunities for system-wide improvements in health equity, resource allocation, and patient outcomes.

## AUSTRALIA'S ROBUST REGULATORY AND GOVERNANCE FRAMEWORK

Australia has a comprehensive suite of legislation, regulation, and oversight bodies to support safe, ethical data sharing, which should alleviate privacy and security concern:

- Privacy Act 1988: Sets out strict requirements for the collection, use, and disclosure of personal and sensitive information, including health data, by both public and private sector organisations. The Act is enforced by the Office of the Australian Information Commissioner (OAIC), which has powers to investigate, enforce, and impose penalties for breaches.
- Office of the Australian Information Commissioner (OAIC): Provides ongoing oversight, guidance, and enforcement for privacy and data protection, including the sharing of information in the public interest and with appropriate safeguards.
- External Request Evaluation Committee (EREC): Provides additional, independent review of data access requests, ensuring that all projects meet ethical, privacy, and public interest standards before data is shared.
- Five Safes Framework: Widely adopted by government data custodians, this internationally recognised approach ensures safe people, projects, settings, data, and outputs for all data sharing activities.
- Ethics Committees: All projects using linked health data must undergo rigorous ethical review, further ensuring that privacy, security, and public benefit are at the core of every data access decision.

These frameworks are not only sufficient but are world-class in their ability to support the safe, secure, and ethical use of health data by trusted, accredited organisations - public, academic, and private alike.

## THE CASE FOR REFORM: UNLOCKING THE VALUE OF HEALTH DATA

As a lead voice for the digital and connected health sector, ANDHealth publishes a bi-annual state of the sector report. In April 2025 the latest report, 'The Rising Giant: Creating a New Economic and Health Future for Australia', was published and showed how Australia's digital and connected health sector now has more than 1,000 companies with a 76% increase since the 2022 report<sup>4</sup>.

The report outlines not only the health impacts the sector is delivering, with a focus on high-impact clinical areas such as mental health and chronic disease management as well as driving system efficiency and

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<sup>3</sup> James Cook University. *Restrictive health data systems limit health care* March 2024.

<https://www.jcu.edu.au/news/releases/2024/march/restrictive-health-data-systems-limit-health-care>

<sup>4</sup> ANDHealth *The Rising Giant: Creating a New Economic and Health Future for Australia* April 2025,

<https://www.andhealth.com.au/insights/insights-the-rising-giant-industry-report>

productivity with clinical decision support software and clinical workflow improvement, but also a growing economic impact with job creation, funds raised, and revenue generated.

Further value and both health and economic impact could be realised with responsible sharing and access of public health data. In addition, the report outlines the rise of the use of artificial intelligence and machine learning in Australian digital and connected health solutions with 22% of all companies primarily using AI as their technology basis, compared to just 14% of companies in 2020. This is important to note as the more credible and diverse the datasets these solutions can be trained from, the higher the efficiency and trustworthiness of solutions<sup>5</sup>.

### **1. Move from Project-by-Project to Programmatic Access**

The current DAT Act implementation requires separate approvals for each project, even for routine, repeatable use cases. This is inefficient and unsuited to the needs of modern analytics and digital health innovation. A programmatic model—where accredited organisations can access pre-approved, high-value datasets for defined public-benefit purposes—would:

- Increase capacity for timely, impactful analysis
- Reduce administrative burden on both applicants and data custodians
- Enable scalable solutions that match the pace of health system needs

### **2. Enable Accreditation of Trusted Non-Government Organisations**

Reform should allow capable private and not-for-profit organisations to become accredited users under the DAT Scheme, subject to:

- A clear public interest test
- Mandatory independent ethics review
- Transparent audit, reporting, and use registers
- Capability-based accreditation, including governance, security, and track record

### **3. Leverage International Best Practice**

Other advanced health systems have demonstrated that trusted, accredited access to de-identified, linked health data by private and not-for-profit organisations can drive innovation, improve health outcomes, and maintain public trust when governed properly.

## **RECOMMENDATIONS**

ANDHealth urges the review to consider the following reforms:

- Retain and strengthen the DAT Act beyond its sunset date, preserving Australia's national data sharing infrastructure for the long term.
- Amend the Act to enable programmatic, accredited access for trusted private and not-for-profit organisations, supported by robust governance and oversight.
- Pilot programmatic access with a limited group of accredited entities, including digital health innovators, to deliver defined, public-benefit analytics projects.
- Harmonise data governance nationally to reduce complexity, improve interoperability, and unlock the full value of Australia's health data assets.

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<sup>5</sup> Digital Health Cooperative Research Centre, *A Call to Action for a National Data Governance Framework* February 2023 [https://researchaustralia.org/wp-content/uploads/2023/02/DHCRC-Call-to-Action-for-a-National-Data-Governance-Framework\\_Feb-2023\\_FINALDESIGNED-1.pdf](https://researchaustralia.org/wp-content/uploads/2023/02/DHCRC-Call-to-Action-for-a-National-Data-Governance-Framework_Feb-2023_FINALDESIGNED-1.pdf)

## CONCLUSION

Australia stands at a crossroads. We possess some of the world's most valuable health datasets, but restrictive access policies mean we are not realising their full potential to improve health outcomes, drive innovation, and maintain our global competitiveness. The regulatory and governance frameworks are already in place to support safe, ethical sharing of public data with the private sector. What is needed now is a modernised, fit-for-purpose DAT Act that enables accredited, trusted organisations—public, academic, and private—to deliver the next generation of health innovation for all Australians.

ANDHealth stands ready to work with government, data custodians, and the broader health sector to help realise this vision.

